NICE National Institute for Health and Care Excellence

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[redacted]

25 June 2024

Mr Oliver Longstaff
Area Coroner for West Yorkshire (Eastern)

Sent via email: [redacted]

Our reference: [redacted]

Dear Mr Longstaff,

Re: Regulation 28 Prevention of Future Deaths Report in respect of Lilly Grace Proctor

I write in response to your regulation 28 report dated 1 May 2024 regarding the very sad death of Lilly Grace Proctor. I would like to express my sincere condolences to Lilly's family.

We have reflected on the circumstances surrounding Lilly's death and the concerns raised in your report. We note your concerns about a lack of guidance on venous thromboembolic disease in children and the lack of child specific screening tools to assist the detection of pulmonary thromboembolism.

Following receipt of your report, senior clinical advisors within the patient safety team at NICE have reviewed the concerns raised. They have advised that incidence of VTE in children is low –1.4-2.1 cases per 100,000 children per year. This is much lower than the incidence in adults. In children, the most common risk factors for VTE are the presence of a central venous catheter (CVC) or conditions such as congenital cardiac disease. Other risk factors include inherited hypercoagulable state (as in this case), infection, trauma, immobility, malignancy, and chronic inflammatory conditions.

Given the rarity of VTE in children, existing NICE guidance on VTE does not include children. Furthermore, the clinical manifestations of severe VTE (such as PE) in children are nonspecific and often mimic the clinical symptoms of other more prevalent diseases.

Regarding a screening tool, there is no specific screening tool that we are aware of. The Wells score and the Caprini score (scores used in adults) have both been evaluated in different paediatric populations, but their performance has not been good, and they cannot be recommended. There is, therefore, no screening tool that NICE could recommend. We note you have mentioned child specific screening tools being developed in other countries, but our clinical advisors are not aware of these and have not seen them used in practice.

In terms of screening for these conditions in relatives of people with inherited thrombophilia, this is also not straightforward, as there are advantages and disadvantages. There are some situations where knowing that a child has an inherited defect may improve medical decision-making, and may give an opportunity to educate about signs and symptoms of VTE, which could lead to earlier diagnosis (as in this case); or to provide targeted thromboprophylaxis in clinical situations where the risk of VTE is increased; and to promote lifestyle modifications to avoid other prothrombotic risk factors (eg, sedentary lifestyle, overweight/obesity, and smoking).

Conversely, inherited thrombophilia testing during childhood may be inappropriate, given the low risk of a thrombotic event; interpretation of screening tests can be challenging and may result in misdiagnosis. There are also ethical concerns about testing in those who may not have the maturity or understanding to make an informed decision. Screening is also problematic in situations where there is no clear medical benefit to the individual being screened.

Nevertheless, NICE will consider the issues raised in your report through our recently implemented organisation-wide approach to prioritisation and topic selection. This is overseen by a single prioritisation board that guides the selection and coordination of our guidance development. We will ask our prioritisation board to consider if guidance should be developed in this area. In line with our usual practice, decisions made by the prioritisation board will be published on the NICE website.

I hope this response has helped outline our role and the reasoning behind our lack of guidance in this specific area and would like to reiterate my sincere condolences to Lilly's family.

Yours sincerely,

Chief Executive